

ALZHEIMER'S DISEASE AND RELATED DEMENTIAS
RESEARCH AMENDMENTS OF 1992

JUNE 29, 1992.—Committed to the Committee of the Whole House on the State of the Union and ordered to be printed

Mr. DINGELL, from the Committee on Energy and Commerce,
submitted the following

R E P O R T

[To accompany H.R. 3082]

[Including cost estimate of the Congressional Budget Office]

The Committee on Energy and Commerce, to whom was referred the bill (H.R. 3082) to amend the Alzheimer's Disease and Related Dementias Services Research Act of 1986 to reauthorize the Act, and for other purposes, having considered the same, report favorably thereon with an amendment and recommend that the bill as amended do pass.

The amendment is as follows:

Strike out all after the enacting clause and insert in lieu thereof the following:

SECTION 1. SHORT TITLE.

This Act may be cited as the "Alzheimer's Disease and Related Dementias Research Amendments of 1992".

SEC. 2. SHORT TITLE OF ACT.

(a) IN GENERAL.—Section 901 of the Alzheimer's Disease and Related Dementias Services Research Act of 1986 (42 U.S.C. 11201 note) is amended by striking "Services Research Act of 1986" and inserting "Research Act of 1992".

(b) CONFORMING AMENDMENT.—Public Law 99-660 is amended in the heading for title IX by striking "SERVICES".

SEC. 3. REFERENCES.

Except as otherwise specifically provided, whenever in this Act an amendment or repeal is expressed in terms of an amendment to, or a repeal of, a section or other provision, the reference shall be considered to be made to that section or other provision of the Alzheimer's Disease and Related Dementias Research Act of 1992, as designated pursuant to the amendment made by section 2 of this Act.

SEC. 4. FINDINGS.

Section 902 (42 U.S.C. 11201) is amended—

(1) by redesignating paragraphs (7) through (12) as paragraphs (9) through (14);

(2) by striking paragraphs (4), (5), and (6); and

(3) by inserting after paragraph (3) the following new paragraphs:

"(4) the cost of caring for individuals with Alzheimer's disease and related dementias is great, and conservative estimates range between \$38,000,000,000 and \$42,000,000,000 per year solely for direct costs;

"(5) progress in the neurosciences and behavioral sciences has demonstrated the interdependence and mutual reinforcement of basic science, clinical research, and services research for Alzheimer's disease and related dementias;

"(6) programs initiated as part of the Decade of the Brain are likely to provide significant progress in understanding the fundamental mechanisms underlying the causes of, and treatments for, Alzheimer's disease and related dementias;

"(7) although substantial progress has been made in recent years in identifying possible leads to the causes of Alzheimer's disease and related dementias, and more progress can be expected in the near future, there is little likelihood of a breakthrough in the immediate future that would eliminate or substantially reduce—

"(A) the number of individuals with the disease and dementias; or

"(B) the difficulties of caring for the individuals;

"(8) the responsibility for care of individuals with Alzheimer's disease and related dementias falls primarily on their families, and the care is very often financially and emotionally devastating;"

SEC. 5. COUNCIL ON ALZHEIMER'S DISEASE.

(a) ESTABLISHMENT.—Section 911 (42 U.S.C. 11211) is amended—

(1) in subsection (a)—

(A) in paragraph (2), by striking "Surgeon General of the United States" and inserting "Surgeon General of the Public Health Service";

(B) in paragraph (6), by striking "and Communicative Diseases" and inserting "Disorders";

(C) by striking paragraphs (10), (11), and (12); and

(D) by adding at the end the following new paragraphs:

"(10) the Administrator for Health Care Policy and Research;

"(11) the Administrator of the Health Resources and Services Administration;

"(12) the Director of the National Center for Nursing Research;

"(13) the Chief Medical Director of the Department of Veterans Affairs;

"(14) the Director of the National Center for Health Statistics; and

"(15) such additional members as the Secretary of Health and Human Services (hereinafter referred to as the 'Secretary') considers appropriate.";

(2) by striking subsection (b) and inserting the following new subsection:

"(b) The Assistant Secretary for Health shall serve as the Chairman of the Council."; and

(3) in subsection (d), by striking "twice" and inserting "once".

(b) FUNCTIONS.—Section 912 (42 U.S.C. 11212) is amended—

(1) in subsection (a)—

(A) by adding "and" at the end of paragraph (3);

(B) by striking "; and" at the end of paragraph (4) and inserting a period; and

(C) by striking paragraph (5); and

(2) by striking subsection (b) and inserting the following new subsection:

"(b)(1) The Chairman of the Council shall annually submit to the committees listed in paragraph (2) a report containing information on—

"(A) progress made by research, sponsored by the Federal Government, on Alzheimer's disease and related dementias; and

"(B) new directions that the Council considers potentially important in research on Alzheimer's disease and related dementias.

"(2) The Chairman of the Council shall submit the report described in paragraph (1) to—

"(A) the Committee on Energy and Commerce of the House of Representatives;

"(B) the Committee on Ways and Means of the House of Representatives;

"(C) the Committee on Veterans' Affairs of the House of Representatives;

"(D) the Select Committee on Aging of the House of Representatives;

"(E) the Committee on Labor and Human Resources of the Senate;

"(F) the Committee on Finance of the Senate;

"(G) the Committee on Veterans' Affairs of the Senate; and

"(H) the Special Committee on Aging of the Senate."

SEC. 6. ADVISORY PANEL ON ALZHEIMER'S DISEASE.

(a) ESTABLISHMENT.—Section 921 (42 U.S.C. 11221) is amended—

(1) in subsection (a)(2), by striking “the Director of the National Center for Health Services Research and Health Care Technology Assessment” and inserting “the Administrator for Health Care Policy and Research”;

(2) in subsection (d), to read as follows:

“(d)(1)(A) Except as provided in subparagraph (B), members of the Panel appointed under subsection (a)(1) shall each serve for a term of 3 years.

“(B) Of the members appointed under subsection (a)(1) that are serving on the Panel on the day before the date of the enactment of this subsection—

“(i) five shall serve for a term that expires on such date;

“(ii) five shall serve for a term that expires 1 year after such date; and

“(iii) five shall serve for a term that expires 2 years after such date.

“(2) A vacancy on the Panel shall be filled in the same manner as the original appointment was made, and not later than 90 days after the date on which the vacancy first arises. A vacancy on the Panel shall not affect the powers of the Panel.”;

(3) in subsection (f), by striking “twice” and inserting “once”;

(4) in subsection (h), by striking “of \$100 per day” and inserting “at the daily equivalent of the maximum rate specified for GS-15 of the General Schedule under section 5332 of title 5, United States Code,”; and

(5) by adding at the end the following new subsection:

“(i) Notwithstanding section 14 of the Federal Advisory Committee Act (5 U.S.C. App.), on September 30, 1994, the Panel shall be abolished and all programs established under this part shall terminate.”.

(b) AUTHORIZATION OF APPROPRIATIONS.—Section 923 (42 U.S.C. 11223) is amended to read as follows:

“SEC. 923. AUTHORIZATION OF APPROPRIATIONS.

“There are authorized to be appropriated to carry out this part such sums as may be necessary for each of the fiscal years 1992 through 1996.”.

SEC. 7. RESEARCH RELATING TO SERVICES FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS AND FAMILIES OF THE INDIVIDUALS.

(a) RESPONSIBILITIES OF THE NATIONAL INSTITUTE OF MENTAL HEALTH.—

(1) GRANTS.—Section 931 (42 U.S.C. 11251) is amended—

(A) by striking subsections (b)(2) and (c);

(B) in subsection (a), by inserting “and specialized care” after “services”; and

(C) in subsection (b)(1)—

(i) by striking “Within 6 months” and all that follows through “plan shall” and inserting “The Director of the National Institute of Mental Health shall”;

(ii) in subparagraph (A)—

(I) by striking “provide for” and inserting “ensure that the research conducted under subsection (a) includes”;

(II) by striking clause (iii) and inserting the following new clause:

“(iii) the optimal range, types, and cost-effectiveness of services and specialized care for individuals with Alzheimer's disease and related dementias and for their families, in community, residential, and institutional settings, particularly with respect to—

“(I) the design of the services and care;

“(II) appropriate staffing for the provision of the services and care;

“(III) the timing of the services and care during the progression of the disease or dementias; and

“(IV) the appropriate mix and coordination of the services and specialized care.”;

(III) in clause (iv), by inserting “the evaluation of best practices for the development of” before “appropriate”; and

(IV) in clauses (v) and (vii), by striking “and nursing home services” and inserting “nursing home services, and other residential services and care”; and

(iii) in subparagraph (B), by striking “research carried out under the plan” and inserting “the research”.

(2) CONFORMING AMENDMENTS.—Section 931(b), as amended by paragraph (1) of this subsection, is amended—

(A) by striking “(1)”;

(B) by redesignating subparagraphs (A) and (B) as paragraphs (1) and (2), respectively;

(C) in paragraph (1) (as so redesignated), by redesignating clauses (i) through (vii) as subparagraphs (A) through (G), respectively; and
 (D) in paragraph (1)(C) (as so redesignated), by redesignating subclauses (I) through (IV) as clauses (i) through (iv), respectively.

(3) **AUTHORIZATION OF APPROPRIATIONS.**—Section 933 (42 U.S.C. 11253) is amended to read as follows:

“SEC. 933. AUTHORIZATION OF APPROPRIATIONS.

“There are authorized to be appropriated to carry out this subpart such sums as may be necessary for each of the fiscal years 1992 through 1996.”.

(b) **RESPONSIBILITIES OF THE AGENCY FOR HEALTH CARE POLICY AND RESEARCH.**—

(1) **RESEARCH PROGRAM AND PLAN.**—Subpart 2 of part D (42 U.S.C. 11261 et seq.) is amended—

(A) in the heading for the subpart, by striking “National Center” and all that follows and inserting the following: “Agency for Health Care Policy and Research”; and

(B) by amending section 934 to read as follows:

“SEC. 934. RESEARCH PROGRAM.

“(a) **GRANTS FOR RESEARCH.**—The Administrator for Health Care Policy and Research shall conduct, or make grants for the conduct of, research relevant to appropriate services for individuals with Alzheimer’s disease and related dementias and for their families.

“(b) **RESEARCH SUBJECTS.**—The Administrator for Health Care Policy and Research shall ensure that research conducted under subsection (a) shall include research concerning—

“(1) improving the organization, delivery, and financing of services for individuals with Alzheimer’s disease and related dementias and for their families, including research on the design, staffing, and operation of special care units for the individuals in institutional settings;

“(2) the costs incurred by individuals with Alzheimer’s disease and related dementias and by their families in obtaining services, particularly services that are essential to the individuals and that are not generally required by other patients under long-term care programs; and

“(3) the costs, cost-effectiveness, and effectiveness of various interventions to provide services for individuals with Alzheimer’s disease and related dementias and for their families.”

(2) **AUTHORIZATION OF APPROPRIATIONS.**—Section 936 (42 U.S.C. 11263) is amended to read as follows:

“SEC. 936. AUTHORIZATION OF APPROPRIATIONS.

“There are authorized to be appropriated to carry out this subpart such sums as may be necessary for each of the fiscal years 1992 through 1996.”.

SEC. 8. TECHNICAL CORRECTION.

Section 782(g)(1)(A) of the Public Health Service Act (42 U.S.C. 295g-2(g)(1)(A)) is amended by inserting “a school of osteopathic medicine,” after “a school of medicine,”.

SUMMARY AND PURPOSE

The purpose of H.R. 3082 is to reauthorize and amend various provisions of the “Alzheimer’s Disease and Related Dementias Services Research Act of 1986.” In particular, the legislation reauthorizes both the Federal Council on Alzheimer’s disease and the Federal Advisory Panel on Alzheimer’s disease for an additional five fiscal years (FY 1992 through FY 1996). For those same fiscal years, H.R. 3082 also provides continued funding for research, training, and education programs on Alzheimer’s disease.

BACKGROUND AND NEED FOR THE LEGISLATION

Alzheimer’s disease—the most common cause of dementia—is a devastating, costly, and eventually deadly neurological disorder that now attacks four million Americans. It is characterized by a deterioration of cognitive functions such as memory, attention, and

judgment. The course of the disease is progressive and irreversible, beginning with simple forgetfulness followed gradually by noticeable and then severe changes in memory and personality. Eventually, the Alzheimer's patient cannot care for himself or herself, and life expectancy is usually reduced.

At the present time, the cause of Alzheimer's is unknown and there is no effective medical treatment for, and no proven method to reduce the risk of, the disease. Other causes of dementia—those known as so-called "related disorders"—present symptoms similar to those found in the Alzheimer's patient and generally speaking, are also without cures, treatments, or risk-reduction measures.

Alzheimer's is found primarily in middle-aged and elderly individuals. It affects one in 10 persons over age 65 and nearly half of those over age 85. The National Institute on Aging projects that the number of individuals in the U.S. with Alzheimer's will double in the next two decades and that the disease will afflict as many as 14 million Americans by the middle of the next century.

The Office of Technology Assessment (OTA) has estimated that in 1985 alone, the medical and related long-term care costs associated with Alzheimer's disease was \$48 billion. This figure does not take into account, however, the additional costs of care provided by family members and friends who often have no choice but to leave their jobs to care for an Alzheimer's patient at home. For 1985, OTA estimates those costs to include some \$32 billion. Adjusted for inflation, then, the total costs that can be attributed to the disease approach \$100 billion in 1992. Neither Medicare nor private health insurance covers any of these costs; Medicaid may reimburse for part, but only for services provided to individuals who have impoverished themselves to meet the Medicaid eligibility requirements. Thus, Alzheimer's disease has been described as the costliest and most uninsured health risk facing older Americans.

In response to these concerns, in 1986, Congress enacted the "Alzheimer's Disease and Related Dementias Services Research Act". The purpose of this legislation is to provide Federal support for research on the cause of, and effective treatment for, Alzheimer's disease and related dementias. In addition, the legislation calls for research on improving the provision of services to both Alzheimer's patients and their families. Since its passage, the Act has supported a number of successful activities in these areas, including the promotion of diagnostic and treatment services for Alzheimer's disease; research on both pharmacological and non-pharmacological treatments of the behaviors associated with Alzheimer's; and research on the specialized care required by Alzheimer's patients living in nursing facilities.

In addition to these efforts, the 1986 law established the Federal Advisory Panel on Alzheimer's Disease. Comprised of experts from both the research and service provider communities, as well as individual consumers, this independent group is mandated to study and make recommendations to the Congress and to the Secretary of Department of Health and Human Services on various issues and concerns related to Alzheimer's disease. To date, the Panel has completed and submitted a series of valuable reports which include recommendations on both Alzheimer's disease science policy and health care delivery policy. Among the areas the Panel has studied

are biomedical research, health services research, service delivery, and financing of health and long-term care services (for both those suffering from Alzheimer's disease and their families). Other reports are currently underway and will be completed in the near future.

The authority for various authorities established under the 1986 Act expired on September 30, 1991. H.R. 3082 is designed to revise, extend, and improve these authorities to allow the good work begun in 1986 to continue.

HEARINGS

On April 15 and 16, 1991, the Subcommittee on Health and the Environment held oversight hearings on programs and activities supported through the National Institutes of Health (NIH), including NIH efforts relating to Alzheimer's disease (Serial No. 102-24). Twenty-five witnesses appeared before the Subcommittee, including the Director of NIH, Dr. Bernadine Healy.

COMMITTEE CONSIDERATION

On March 26, 1992, the Subcommittee on Health and the Environment met in open session and ordered reported the bill H.R. 3082, as amended, by voice vote, a quorum being present. On April 7, 1992, the Committee met in open session and ordered reported the bill, H.R. 3082, as amended, by voice vote, a quorum being present.

COMMITTEE OVERSIGHT FINDINGS

Pursuant to clause 2(1)(3)(A) of Rule XI of the Rules of the House of Representatives, the Subcommittee held oversight hearings and made findings that are reflected in the legislative report.

COMMITTEE ON GOVERNMENT OPERATIONS

Pursuant to clause 2(1)(3)(D) of rule XI of the Rules of the House of Representatives, no oversight findings have been submitted to the Committee by the Committee on Government Operations.

COMMITTEE COST ESTIMATE

In compliance with clause 7(a) of rule XIII of the Rules of the House of Representatives, the Committee believes that the costs incurred in carrying out H.R. 3082 would be \$3 million for fiscal year 1992; \$35 million for fiscal year 1993; \$69 million for fiscal year 1994; \$73 million for fiscal year 1995; and \$71 million for fiscal year 1996.

CONGRESSIONAL BUDGET OFFICE ESTIMATE

U.S. CONGRESS,
CONGRESSIONAL BUDGET OFFICE,
Washington, DC, May 5, 1992.

Hon. JOHN D. DINGELL,
Chairman, Committee on Energy and Commerce, United States
House of Representatives, Washington, DC.

DEAR MR. CHAIRMAN: The Congressional Budget Office has prepared the enclosed cost estimate for H.R. 3082, the Alzheimer's Disease and Related Dementias Research Amendments of 1992, as ordered reported by the House Committee on Energy and Commerce on April 7, 1992. Enactment of H.R. 3082 would not affect direct spending or receipts. Therefore, pay-as-you-go procedures would not apply to this bill.

If you wish further details on this estimate, we will be pleased to provide them.

Sincerely,

JAMES L. BLUM
(For Robert D. Reischauer, Director).

CONGRESSIONAL BUDGET OFFICE—COST ESTIMATE

1. Bill number: H.R. 3082.
2. Bill title: Alzheimer's Disease and Related Dementias Research Amendments of 1992.
3. Bill status: As ordered reported by the House Energy and Commerce Committee on April 7, 1992.
4. Bill purpose: To amend the Alzheimer's Disease and Related Dementias Services Research Act of 1986 to reauthorize the Act, and for other purposes.
5. Estimated cost to the Federal Government:

[By fiscal years, in millions of dollars]

	1992	1993	1994	1995	1996	1997
Estimated authorizations:						
Advisory panel.....	*	*	*	*	*	*
NIMH research.....	0	28	29	30	31
AHCPR research.....	5	7	8
Alzheimer's centers.....	2	37	38	39	41
Total estimated authorization	7	72	75	70	72
Estimated outlays:						
Advisory panel.....	*	*	*	*	*	*
NIMH research.....	0	12	27	30	31	18
AHCPR research.....	2	6	7	5	*	0
Alzheimer's centers.....	1	17	35	38	40	23
Total estimated outlays	3	35	69	73	71	41

* Less than \$500,000.

Estimated amounts may not add to totals because of rounding.

Basis of estimate: H.R. 3082 would reauthorize funding for an Advisory Panel on Alzheimer's Disease, at such sums as may be necessary for each of fiscal years 1992 through 1996. The Advisory

Panel was funded during fiscal year 1991 at \$100,000. The panel has not been funded so far in fiscal year 1992. CBO estimated the authorization levels for fiscal years 1992 through 1996 by adjusting the fiscal year 1991 appropriation for projected inflation.

The bill would reauthorize funding for research at the National Institute of Mental Health (NIMH) relating to services for individuals with Alzheimer's disease, and families of the individuals. The bill authorizes appropriations of such sums as may be necessary for each of fiscal years 1992 through 1996 for this program. NIMH funded research on Alzheimer's disease at \$26 million in fiscal year 1991, when the previous authorization for this program expired. CBO estimated the authorization levels for fiscal years 1993 through 1996 by adjusting the fiscal year 1991 funding level for projected inflation. This approach would yield \$27 million for 1992, but the table shows no additional amounts authorized for appropriation for that year. CBO's estimate for 1992 is based on information from NIMH that indicates that more than \$27 million will be spent on the program in 1992 under general authority that currently exists.

H.R. 3082 would reauthorize funding for research by the Agency for Health Care Policy and Research (AHCOR), regarding appropriate services for individuals with Alzheimer's disease and related dementias and for their families. The bill specifically authorizes \$6 million for the program in fiscal year 1992 but current funding is only about \$500,000. CBO's estimate of the amount authorized in fiscal year 1992 is the difference between these two amounts. The bill specifically authorizes appropriations of \$7 million for fiscal year 1993, and \$8 million for fiscal year 1994 for this program.

The bill would reauthorize funding for Alzheimer's Disease Centers, at such sums as may be necessary for fiscal year 1992 and each of the subsequent fiscal years. In fiscal year 1991, Alzheimer's Disease Centers were funded at \$34 million, when the previous authorization for this program expired. CBO estimated the fiscal year 1993 through 1996 authorization amounts by adjusting the fiscal year 1991 appropriation for projected inflation. CBO's estimate for additional authorization in 1992 is \$2 million, which is the difference between the 1991 level increased for inflation and the amount of 1992 funding for the centers under existing general authority.

6. Pay-as-you-go considerations: The Budget Enforcement Act of 1990 sets up pay-as-you-go procedures for legislation affecting direct spending or receipts through 1995. None of the provisions of H.R. 3082 would affect direct spending or receipts. Therefore, this bill has no pay-as-you-go implications.

7. Estimated cost to State and local government: None.

8. Estimate comparison: None.

9. Previous CBO estimate: None.

10. Estimate prepared by: Connie Takata.

11. Estimate approved by: C.G. Nuckols, Assistant Director for Budget Analysis.

INFLATION IMPACT STATEMENT

Pursuant to clause 2(1)(4) of rule XI of the Rules of the House of Representatives, the Committee makes the following statement with regard to the inflationary impact of the reported bill:

The Committee is unaware of any inflationary impact that H.R. 3082 would have on the Nation's economy. The funds authorized under this legislation represent a small share of the Federal budget and would provide the necessary financial support to maintain and improve the activities authorized under the "Alzheimer's Disease and Related Dementias Services Research Act of 1986".

The Committee notes that the primary purpose of H.R. 3082 is to provide support for a variety of programs designed to address the treatment and other health care needs of individuals with Alzheimer's disease and related disorders. Such programs can help both to improve the lives of these individuals and their families and to reduce the significant health costs associated with Alzheimer's disease. Thus, in the view of the Committee, the cost-benefit ratio of H.R. 3082 is clearly anti-inflationary.

ANALYSIS OF LEGISLATION

H.R. 3082 would revise and extend through FY 1996 various authorities established under the "Alzheimer's Disease and Related Dementias Services Research Act of 1986". In particular, the legislation would reauthorize both the Federal Council on Alzheimer's Disease and the Federal Advisory Panel on Alzheimer's Disease. In addition, the legislation would make minor improvements in the authority and operation of the Council and the Advisory Panel, but leave in force the 1986 mandate for each of these organizations. Thus, the Council is to continue its primary work in coordinating efforts among the various Federal agencies which sponsor or support research on Alzheimer's disease and related disorders. Similarly, the Advisory Panel is to continue its primary task in bringing together the best thinking of the scientific and public policy communities to advise the Congress and the Secretary on a variety of issues related to these diseases and disorders.

H.R. 3082 would also revise and extend through FY 1996 the authorities under the National Institute for Mental Health (NIMH) and the Agency for Health Care Policy and Research (AHCPR) for research on appropriate services for Alzheimer's patients and their families. The Committee is particularly interested in the work now underway at AHCPR on the development of clinical guidelines for the conduct of assessments of individuals with dementia and would encourage that agency to complete this effort as soon as possible. The Committee is also interested in research on the service needs of persons with Alzheimer's disease that may be dependent on where a patient is residing: at home, in the community, or in an institution. In the Committee's view, such research will produce data and information that should be useful as Congress begins to debate proposed legislation to address the Nation's long-term care crisis. H.R. 3082 includes, therefore, new authority for NIMH to carry out this research.

AGENCY VIEWS

No agency views were received by the Committee on H.R. 3082.

CHANGES IN EXISTING LAW MADE BY THE BILL, AS REPORTED

In compliance with clause 3 of rule XIII of the Rules of the House of Representatives, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italics, existing law in which no change is proposed is shown in roman):

**ALZHEIMER'S DISEASE AND RELATED DEMENTIAS
SERVICES RESEARCH ACT OF 1986**

**TITLE IX—ALZHEIMER'S DISEASE AND RELATED
DEMENTIAS [SERVICES] RESEARCH**

PART A—GENERAL PROVISIONS

SHORT TITLE

SEC. 901. This title may be cited as the "Alzheimer's Disease and Related Dementias [Services Research Act of 1986] *Research Act of 1992*".

FINDINGS

SEC. 902. The Congress finds that—

(1) * * *

* * * * *

[(4) the care for individuals with Alzheimer's disease and related dementias falls primarily on their families, and such care is very often financially and emotionally devastating;

[(5) the cost of caring for individuals with Alzheimer's disease and related dementias is great, and conservative estimates range between \$38,000,000,000 and \$42,000,000,000 per year solely for direct costs;

[(6) although substantial progress has been made in recent years in identifying possible leads to the causes of Alzheimer's disease and related dementias and more progress can be expected in the near future, there is little likelihood of a breakthrough in the foreseeable future which would eliminate or substantially reduce the number of individuals with such disease and dementias or the difficulties of caring for such individuals;]

(4) the cost of caring for individuals with Alzheimer's disease and related dementias is great, and conservative estimates range between \$38,000,000,000 and \$42,000,000,000 per year solely for direct costs;

(5) progress in the neurosciences and behavioral sciences has demonstrated the interdependence and mutual reinforcement of basic science, clinical research, and services research for Alzheimer's disease and related dementias;

(6) *programs initiated as part of the Decade of the Brain are likely to provide significant progress in understanding the fundamental mechanisms underlying the causes of, and treatments for, Alzheimer's disease and related dementias;*

(7) *although substantial progress has been made in recent years in identifying possible leads to the causes of Alzheimer's disease and related dementias, and more progress can be expected in the near future, there is little likelihood of a breakthrough in the immediate future that would eliminate or substantially reduce—*

(A) *the number of individuals with the disease and dementias; or*

(B) *the difficulties of caring for the individuals;*

(8) *the responsibility for care of individuals with Alzheimer's disease and related dementias falls primarily on their families, and the care is very often financially and emotionally devastating;*

[(7)] (9) *attempts to reduce the emotional and financial burden of caring for dementia patients is impeded by a lack of knowledge about such patients, how to care for such patients, the costs associated with such care, the effectiveness of various modes of care, the quality and type of care necessary at various stages of the disease, and other appropriate services that are needed to provide quality care;*

[(8)] (10) *the results of the little research that has been undertaken concerning dementia has been inadequate or the results have not been widely disseminated;*

[(9)] (11) *more knowledge is needed concerning—*

(A) *the epidemiology of, and the identification of risk factors for, Alzheimer's disease and related dementias;*

(B) *the development of methods for early diagnosis, functional assessment, and psychological evaluation of individuals with Alzheimer's disease for the purpose of monitoring the course of the disease and developing strategies for improving the quality of life for such individuals;*

(C) *the understanding of the optimal range and cost-effectiveness of community and institutional services for individuals with Alzheimer's disease and related dementias and their families, particularly with respect to the design, delivery, staffing, and mix of such services and the coordination of such services with other services, and with respect to the relationship of formal to informal support services;*

(D) *the understanding of optimal methods to combine formal support services provided by health care professionals with informal support services provided by family, friends, and neighbors of individuals with Alzheimer's disease, and the identification of ways family caregivers can be sustained through interventions to reduce psychological and social problems and physical problems induced by stress;*

(E) *existing data that are relevant to Alzheimer's disease and related dementias; and*

(F) the costs incurred in caring for individuals with Alzheimer's disease and related dementias;

[(10)] (12) it is imperative to provide appropriate coordination of the efforts of the Federal Government in the provision of services for individuals with Alzheimer's disease and related dementias;

[(11)] (13) it is important to increase the understanding of Alzheimer's disease and related dementias by the diverse range of personnel involved in the care of individuals with such disease and dementias; and

[(12)] (14) it is imperative that the Social Security Administration be provided information pertaining to Alzheimer's disease and related dementias, particularly for personnel in such Administration involved in the establishment and updating of criteria for determining whether an individual is under a disability for purposes of titles II and XVI of the Social Security Act.

PART B—COUNCIL ON ALZHEIMER'S DISEASE

ESTABLISHMENT

SEC. 911. (a) There is established in the Department of Health and Human Services (hereinafter referred to as the "Department") the Council on Alzheimer's Disease (hereinafter referred to as the "Council"). The Council shall be composed of—

(1) the Assistant Secretary for Health;

(2) the Surgeon General of the [United States] *Public Health Service*;

(3) the Assistant Secretary for Planning and Evaluation;

(4) the Director of the National Institute of Allergy and Infectious Diseases;

(5) the Director of the National Institute of Mental Health;

(6) the Director of the National Institute of Neurological [and Communicative Diseases] *Disorders and Stroke*;

(7) the Director of the National Institute on Aging;

(8) the Commissioner on Aging;

(9) the Administrator of the Health Care Financing Administration (or the designee of such Administrator);

[(10)] the Director of the National Center for Health Services Research and Health Care Technology Assessment;

[(11)] the Secretary of Veterans Affairs (or the designee of such Secretary); and

[(12)] such additional members as the Secretary of Health and Human Services (hereinafter referred to as the "Secretary") considers appropriate.]

(10) *the Administrator for Health Care Policy and Research;*

(11) *the Administrator of the Health Resources and Services Administration;*

(12) *the Director of the National Center for Nursing Research;*

(13) *the Chief Medical Director of the Department of Veterans Affairs;*

(14) *the Director of the National Center for Health Statistics;*
and

(15) such additional members as the Secretary of Health and Human Services (hereinafter referred to as the "Secretary") considers appropriate.

[(b) The Secretary shall select a Chairman for the Council from among its members.]

(b) The Assistant Secretary for Health shall serve as the Chairman of the Council.

* * * * *

(d) The Council shall meet periodically at the call of the Chairman, but not less than [twice] once each year.

* * * * *

FUNCTIONS

SEC. 912. (a) The Council shall—

(1) * * *

* * * * *

(3) identify the most promising areas of research concerning Alzheimer's disease and related dementias; and

(4) establish mechanisms to use the results of research concerning Alzheimer's disease and related dementias in the development of policies, programs, and means to improve the quality of life for older Americans[; and].

[(5) assist the National Institute on Aging, the National Institute of Mental Health, and the National Center for Health Services Research and Health Care Technology Assessment in developing and coordinating the plans for research required under part E, and in making revisions in such plans.

[(b)(1) Not later than 9 months after the date of enactment of this Act, the Council shall transmit to the Congress and make available to the public a report detailing the plans for research prepared by the National Institute on Aging, the National Institute of Mental Health, and the National Center for Health Services Research and Health Care Technology Assessment under part D. Such report shall—

[(A) describe, insofar as feasible, the activities to be carried out under such part during each of the fiscal years 1987, 1988, 1989, 1990, and 1991; and

[(B) ensure that activities carried out under such part are coordinated with, and use, to the maximum extent feasible, the resources of, other Federal programs relating to Alzheimer's disease and related dementias, including centers supported under section 445 of the Public Health Service Act, centers supported by the National Institute of Mental Health on the psychopathology of the elderly, relevant activities of the Administration on Aging, other centers supported by Federal funds involved in research on Alzheimer's disease and related dementias, and other programs relating to Alzheimer's disease and related dementias which are planned or conducted by Federal agencies other than the Department, State or local agencies, community organizations, or private foundations.

[(2) Within 1 year after the date on which the report required by paragraph (1) is transmitted to the Congress, and annually thereafter

ter, the Council shall transmit to the Congress, and make available to the public, a report on—

[(A) the revisions made by the National Institute on Aging, the National Institute of Mental Health, and the National Center for Health Services Research and Health Care Technology Assessment in the plans for research required by part E;

[(B) progress made by research sponsored by the Federal Government on Alzheimer's disease and related dementias; and

[(C) new directions in research on Alzheimer's disease and related dementias which the Council considers potentially important.]

(b)(1) *The Chairman of the Council shall annually submit to the committees listed in paragraph (2) a report containing information on—*

(A) progress made by research, sponsored by the Federal Government, on Alzheimer's disease and related dementias; and

(B) new directions that the Council considers potentially important in research on Alzheimer's disease and related dementias.

(2) The Chairman of the Council shall submit the report described in paragraph (1) to—

(A) the Committee on Energy and Commerce of the House of Representatives;

(B) the Committee on Ways and Means of the House of Representatives;

(C) the Committee on Veterans' Affairs of the House of Representatives;

(D) the Select Committee on Aging of the House of Representatives;

(E) the Committee on Labor and Human Resources of the Senate;

(F) the Committee on Finance of the Senate;

(G) the Committee on Veterans' Affairs of the Senate; and

(H) the Special Committee on Aging of the Senate.

PART C—ADVISORY PANEL ON ALZHEIMER'S DISEASE

ESTABLISHMENT OF PANEL

SEC. 921. (a) There is established in the Department the Advisory Panel on Alzheimer's Disease (hereinafter referred to as the "Panel"). The Panel shall be composed of—

(1) * * *

* * * * *

(2) the Chairman of the Council, the Director of the National Institute on Aging, the Director of the National Institute of Mental Health, [the Director of the National Center for Health Services Research and Health Care Technology Assessment] the Administrator for Health Care Policy and Research, and the Commissioner on Aging, who shall be nonvoting ex officio members.

* * * * *

[(d) Members of the Panel shall serve for the life of the Panel. A vacancy on the Panel shall be filled in the same manner as the original appointment was made. A vacancy on the Panel shall not affect its powers.]

(d)(1)(A) Except as provided in subparagraph (B), members of the Panel appointed under subsection (a)(1) shall each serve for a term of 3 years.

(B) Of the members appointed under subsection (a)(1) that are serving on the Panel on the day before the date of the enactment of this subsection—

(i) five shall serve for a term that expires on such date;

(ii) five shall serve for a term that expires 1 year after such date; and

(iii) five shall serve for a term that expires 2 years after such date.

(2) A vacancy on the Panel shall be filled in the same manner as the original appointment was made, and not later than 90 days after the date on which the vacancy first arises. A vacancy on the Panel shall not affect the powers of the Panel.

* * * * *

(f) The Panel shall meet at the call of the Chairman, but not less than [twice] once per year.

* * * * *

(h) Each member of the Panel appointed under subsection (a)(1) shall receive compensation at a rate [of \$100 per day] *at the daily equivalent of the maximum rate specified for GS-15 of the General Schedule under section 5332 of title 5, United States Code*, for each day, including travel time, that such member is engaged in duties as a member of the Panel. While away from their homes or regular places of business in the performance of duties as a member of the Panel, members of the Panel appointed under subsection (a)(1) shall be allowed travel expenses, including per diem in lieu of subsistence, at rates authorized for employees of agencies under section 5702 of title 5, United States Code.

(i) Notwithstanding section 14 of the Federal Advisory Committee Act (5 U.S.C. App.), on September 30, 1994, the Panel shall be abolished and all programs established under this part shall terminate.

* * * * *

[AUTHORIZATION OF APPROPRIATIONS

[SEC. 923. To carry out this part, there are authorized to be appropriated \$100,000 for each of the fiscal years 1988 through 1991.]

SEC. 923. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this part such sums as may be necessary for each of the fiscal years 1992 through 1996.

PART D—RESEARCH RELATING TO SERVICES FOR INDIVIDUALS WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIAS AND THEIR FAMILIES

Subpart 1—Responsibilities of the National Institute of Mental Health

RESEARCH PROGRAM AND PLAN

SEC. 931. (a) The Director of the National Institute of Mental Health shall conduct, or make grants for the conduct of, research relevant to appropriate services *and specialized care* for individuals with Alzheimer's disease and related dementias and their families.

(b) [(1) Within 6 months after the date of enactment of this Act, the Director of the National Institute of Mental Health shall prepare and transmit to the Chairman of the Council a plan for the research to be conducted under subsection (a). The plan shall] *The Director of the National Institute of Mental Health shall—*

[(A)] (1) [provide for] *ensure that the research conducted under subsection (a) includes research concerning—*

[(i)] (A) *mental health services and treatment modalities relevant to the mental, behavioral, and psychological problems associated with Alzheimer's disease and related dementias;*

[(ii)] (B) *the most effective methods for providing comprehensive multidimensional assessments to obtain information about the current functioning of, and needs for the care of, individuals with Alzheimer's disease and related dementias;*

[(iii)] *the optimal range and cost-effectiveness of community and institutional services for individuals with Alzheimer's disease and related dementias and their families, particularly with respect to the design of such services, appropriate staffing for the provision of such services, the timing of such services during the progression of such disease or dementias, and the appropriate mix and coordination of such services;*

(C) the optimal range, types, and cost-effectiveness of services and specialized care for individuals with Alzheimer's disease and related dementias and for their families, in community, residential, and institutional settings, particularly with respect to—

(i) the design of the services and care;

(ii) appropriate staffing for the provision of the services and care;

(iii) the timing of the services and care during the progression of the disease or dementias; and

(iv) the appropriate mix and coordination of the services and specialized care;

[(iv)] (D) *the efficacy of various special care units in the United States for individuals with Alzheimer's disease, including an assessment of the costs incurred in operating such units, the evaluation of best practices for the development of appropriate standards to be used by such units, and the measurement of patient outcomes in such units;*

[(v)] (E) methods to combine formal support services provided by health care professionals for individuals with Alzheimer's disease and related dementias with informal support services provided for such individuals by their families, friends, and neighbors, including services such as day care services, respite care services, home care services, [and nursing home services] *nursing home services, and other residential services and care*, and an evaluation of the services actually used for such individuals and the sources of payment for such services;

[(vi)] (F) methods to sustain family members who provide care for individuals with Alzheimer's disease and related dementias through interventions to reduce psychological and social problems and physical problems induced by stress; and

[(vii)] (G) improved methods to deliver services for individuals with Alzheimer's disease and related dementias and their families, including services such as outreach services, comprehensive assessment and care management services, outpatient treatment services, home care services, respite care services, adult day care services, partial hospitalization services, [and nursing home services] *nursing home services, and other residential services and care*; and

[(B)] (2) ensure that [research carried out under the plan] *the research* is coordinated with, and uses, to the maximum extent feasible, resources of, other Federal programs relating to Alzheimer's disease and dementia, including centers supported under section 445 of the Public Health Service Act, centers supported by the National Institute of Mental Health on the psychopathology of the elderly, relevant activities of the Administration on Aging, other programs and centers involved in research on Alzheimer's disease and related dementias supported by the Department, and other programs relating to Alzheimer's disease and related dementias which are planned or conducted by Federal agencies other than the Department, State or local agencies, community organizations, or private foundations.

[(2) Within one year after transmitting the plan required under paragraph (1), and annually thereafter, the Director of the National Institute of Mental Health shall prepare and transmit to the Chairman of the Council such revisions of such plan as the Director considers appropriate.

[(c) In preparing and revising the plan required by subsection (b), the Director of the National Institute of Mental Health shall consult with the Chairman of the Council and the heads of agencies within the Department.]

* * * * *

[AUTHORIZATION OF APPROPRIATIONS]

[SEC. 933. To carry out this subpart, there are authorized to be appropriated \$2,000,000 for each of fiscal years 1988 through 1991.]

SEC. 933. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this subpart such sums as may be necessary for each of the fiscal years 1992 through 1996.

Subpart 2—Responsibilities of the [National Center for Health Services Research and Health Care Technology Assessment]
Agency for Health Care Policy and Research

[RESEARCH PROGRAM AND PLAN

[SEC. 934. (a) The Director of the National Center for Health Services Research and Health Care Technology Assessment shall conduct, or make grants for the conduct of, research relevant to appropriate services for individuals with Alzheimer's disease and related dementias and their families.

[(b)(1)] Within 6 months after the date of enactment of this Act, the Director of the National Center for Health Services Research and Health Care Technology Assessment shall prepare and transmit to the Chairman of the Council a plan for the research to be conducted under subsection (a). The plan shall—

[(A)] provide for the inventory and analysis of existing data and studies relevant to Alzheimer's disease and related dementias, including data and studies available through the Health Care Financing Administration, the Administration on Aging, the National Center for Health Statistics, the Office of Human Development Services, the Office of the Assistant Secretary for Planning and Evaluation, and the Department of Veterans Affairs;

[(B)] provide for research concerning the costs incurred by individuals with Alzheimer's disease and related dementias in obtaining services, particularly services which are essential to such individuals and which are not needed by other patients under long-term care;

[(C)] provide for research on the costs of various interventions to provide services for individuals with Alzheimer's disease and related dementias and their families;

[(D)] provide for research on the cost-effectiveness of various service interventions for individuals with Alzheimer's disease and related dementias and their families; and

[(E)] ensure that research carried out under the plan is coordinated with, and uses, to the maximum extent feasible, resources of, other Federal programs relating to Alzheimer's disease and dementia, including centers supported under section 445 of the Public Health Service Act, centers supported by the National Institute of Mental Health on psychopathology of the elderly, relevant activities of the Administration on Aging, other programs and centers involved in research on Alzheimer's disease and related dementias supported by the Department, and other programs relating to Alzheimer's disease and related dementias which are planned or conducted by Federal agencies other than the Department, State or local agencies, community organizations, or private foundations.

[(2) Within one year after transmitting the plan required under paragraph (1), and annually thereafter, the Director of the National Center for Health Services Research and Health Care Technology Assessment shall prepare and transmit to the Chairman of the Council such revisions of such plan as the Director considers appropriate.]

[(c) In preparing and revising the plan required by subsection (b), the Director of the National Center for Health Services Research and Health Care Technology Assessment¹ shall consult with the Chairman of the Council and the heads of agencies within the Department.]

SEC. 934. RESEARCH PROGRAM.

(a) *GRANTS FOR RESEARCH.*—The Administrator for Health Care Policy and Research shall conduct, or make grants for the conduct of, research relevant to appropriate services for individuals with Alzheimer's disease and related dementias and for their families.

(b) *RESEARCH SUBJECTS.*—The Administrator for Health Care Policy and Research shall ensure that research conducted under subsection (a) shall include research concerning—

(1) improving the organization, delivery, and financing of services for individuals with Alzheimer's disease and related dementias and for their families, including research on the design, staffing, and operation of special care units for the individuals in institutional settings;

(2) the costs incurred by individuals with Alzheimer's disease and related dementias and by their families in obtaining services, particularly services that are essential to the individuals and that are not generally required by other patients under long-term care programs; and

(3) the costs, cost-effectiveness, and effectiveness of various interventions to provide services for individuals with Alzheimer's disease and related dementias and for their families.

* * * * *

[AUTHORIZATION OF APPROPRIATIONS]

[SEC. 936. To carry out this subpart, there are authorized to be appropriated \$2,000,000 for each of fiscal years 1988 through 1991.]

SEC. 936. AUTHORIZATION OF APPROPRIATIONS.

There are authorized to be appropriated to carry out this subpart such sums as may be necessary for each of the fiscal years 1992 through 1996.

SECTION 782 OF THE PUBLIC HEALTH SERVICE ACT

PROGRAMS OF EXCELLENCE IN HEALTH PROFESSIONS EDUCATION FOR MINORITIES

SEC. 782. (a) * * *

* * * * *

(g) *DEFINITIONS.*—For purposes of this section:

(1)(A) The term "health professions school" means, except as provided in subparagraph (B), a school of medicine, *a school of osteopathic medicine*, a school of dentistry, or a school of pharmacy.

(B) The definition established in subparagraph (A) shall not apply to the use of the term "health professions school" for purposes of subsection (c)(2).

(2) The term "program of excellence" means any program carried out by a health professions school with a grant made under subsection (a), if the program is for purposes for which the school involved is authorized in subsection (b) or (c) to expend the grant.

(3) The term "Native Americans" means American Indians, Alaskan Natives, Aleuts, and Native Hawaiians.

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